

Appropriations Committee
Public Hearing Testimony
Thursday, March 4, 2011

Re: The Brain Injury Association of Connecticut as affected by H.B. No. 6380 AN ACT CONCERNING THE BUDGET FOR THE BIENNIUM ENDING JUNE 30, 2013.

Good Evening Chairman Harp, Chairman Walker, and Appropriations Committee Membership. My name is Julie LaChappelle, I reside in Eastford, CT, and I would like to thank you for allowing me the opportunity to testify in opposition of the elimination of the Brain Injury Association of Connecticut's operating grant.

March is Brain Injury Awareness month, and thanks to the messages put out to the public by the organizations involved with those affected by brain injury, many people will take a moment to think about brain injury when they otherwise might not have. They might think about what a traumatic brain injury is, how it could occur, or how terrible it would be if they or someone they loved were to suffer a head injury. But for me and my family, each and every one of the last 16 months has been about brain injury awareness. And ironically, that is also because of the messages and the decisions of the agencies and organizations created to help those affected by brain injury. Except the message to my family, and to my sister, who suffered a TBI in an auto accident in October 2009, has not been that someone is there to help, or that anyone has answers for our questions. The message has been that Connecticut is not a place that wants you here if you have a brain injury. The message has been that there is a limited and narrowly defined set of options unless you fall into a preauthorized category for which there has been a decision that the need should be met.

Connecticut is viewed by many health care professionals as "the black hole" for neurological rehabilitation. I can personally attest to the truth of that statement. Three months after my sister's accident, she was deemed medically stable enough for discharge from Hartford Hospital, despite her extremely vulnerable and medically complex situation. We were pressured to find another place to go, but our father's insurance policy (provided by Anthem Blue Cross Blue Shield through his state employment) would not cover her stay at a rehab facility until she became more able to actively participate in rehab and showed progress. It seemed that her life as an active member of society was not a worthwhile investment for Blue Cross Blue Shield, so we applied and were able to receive CT Medicaid/Title 19. Having the Medicaid benefits, we were given two options: to send Allie to an elderly nursing home in CT, or to the Neurological Rehab Center in Worcester, MA; the only out-of-state facility contracted with CT Medicaid. Believing it would be the better choice, we admitted Allie to the Worcester Neuro Rehab Center where she spent six miserable, wasteful months, in and out of the hospital continuously. The care was so atrocious and our complaints so readily dismissed that I reported them to the MA Department of Public Health.

After spending another 3 months in UMass Memorial Hospital for various medical complications, she was again determined to be stable and I began searching for another rehab center, as we would not allow Allie to return to the Worcester Neuro Rehab. It took another 2 months to find somewhere else to go, and it came down to two options out of the 85 places to which we applied. Blue Cross forced us to receive denials from every nursing home in CT before we could start looking out of state, and even then, refused to pay for any rehab services at all. They tried to force my 19-year-old sister into nursing homes with paragraphs of health inspection violations and deficiencies, just like the Worcester Neuro Rehab. We were receiving pressure to leave the hospital daily, but I received little help from the five care coordinators at UMass, our Blue Cross case manager, or our contact at Dept of Social Services.

I used Google to search for facilities and research their inspection reports and patient/family reviews, but nowhere that we deemed appropriate would accept her. It was at this point that I reached out the Brain Injury Association of CT to see if they had a list of possible options for my sister. They apologetically expressed frustration when they told me that they did not have any suggestions, as there simply are no sub-acute neuro-rehabs in CT. They told me that they receive and, must deny, this same request from countless others, and recommended that I contact my legislators to advocate for change. I have since contacted dozens of representatives and senators, including many of you, as well as the attorney general, Governor, and Lieutenant Governor. I am now working with the Brain Injury Advisory Board, hoping to testify again soon in support of a bill to establish the Board through state statute and report directly to the Governor.

Four months ago Allie was finally admitted to a remarkable facility, which unfortunately is located two hours away from our home, in northern Massachusetts. It was never made known to us that asking an out-of-state facility to enroll with CT Medicaid was an option; it was the admissions dept that suggested it to us. Thanks to the unparalleled level of therapy she now receives, my amazing sister has made more progress in these past few months than we ever expected. Now, instead of having to spend hours every week ensuring she receives proper care, I can focus my efforts on improving the situation in our home state, hopefully making it possible for her to finally return.

As a tax-paying participant of the democratic process I am asking you to make changes to funding for neurological rehab centers in CT, to support funding for coma stimulation units in hospitals or other facilities, and to make changes to Medicaid and state insurance policy contracts with out-of-state rehabs so no one else has to endure the battle for treatment that we have. The story of Allie's struggle to regain her wellness should only be about her battle through the medical trauma, the healing from countless surgeries, infections, and complications, and about her steady gains through physical and occupational therapies. Instead, that story is almost overshadowed by the difficulties of navigating our way through the denials and limitations of our private insurance, Medicaid, and available treatment facilities.

It is appalling and unacceptable that in a state as affluent as Connecticut, where there are countless prisons and addiction treatment services and rehabs, it was so

difficult to find help for a young girl that has been struggling to regain her life and wellness. The state needs to be paying more attention and providing greater support to this cause, not less. The business of insurance and health care is determining the future of my sister and so many others. Our state makes it clear that they don't want to deal with finding solutions to the problems presented by brain injury, nor does the medical field, it seems, because it is too large of an investment with too high a risk of return. We have met countless patients in the same position who do not have the capability of fighting for themselves the way I am fighting for my sister, and thus I am fighting for them too. Treatment for traumatic brain injury is one of Connecticut's greatest deficiencies in citizen representation, and to further reduce their support would be a callous and inexcusable offense.

I urge you to voice your opposition to the proposed funding cut to the Brain Injury Association of CT. Thank you for allowing me to speak on behalf of my sister this evening. We very much appreciate your time and consideration and look forward to your continued support.

Sincerely,

Julie LaChappelle